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ABSTRACT

Issues in the provision of lifelong care for a handicapped son or daughter are discussed. Three types of guardianship are described: total guardianship, partial or limited guardianship, and collective guardianship/joint trust. Topics addressed include reasons for setting up a trust, specific trust provisions, terminating the trust, social security and other benefits, life insurance, and the disposition of savings. Selection of a trustee or guardian, the guardian's role, and record-keeping for the guardian are also discussed. A section of do's and don'ts includes the recommendation to select an attorney experienced in setting up trust agreements and wills for the handicapped. (JW)

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Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 3, NO. 3 MAY/JUNE 1987

GUARDIANSHIP

One of the major concerns of the special parent is "what will happen to my special son or daughter after I'm gone?" Safeguarding the welfare of the disabled individual after the death of the parent is a frightening aspect. The laws of this country assume that anyone who has reached age 18 is an adult, fully capable and responsible for his own actions. The laws **do not** acknowledge the special needs of the handicapped child or adult **unless** the parent specifically arranges for **protection and guardianship.** In response to overwhelming inquiries and readership concern, this issue will focus on those steps necessary to provide lifelong care for your special son or daughter.

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L. Murphy

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

What is guardianship?

Guardianship is more than selecting someone to oversee the day-to-day living conditions of the handicapped individual after the death of the parent. Guardianship is a **court-approved relationship** between a legal guardian and the handicapped person.

When your special child reaches age 18, the law considers him an adult. You must legally request the right to be appointed as your child's own guardian! Unless you do so you have no legal right to make any decisions on your special child's behalf, including consent to surgery or other vital matters. The guardian is given the right by the courts to make important decisions regarding the welfare of the disabled person.

There are several types of guardianship, each one with its own advantages and disadvantages, so it's a good idea to seek professional advice on which one is best for your special child. Keep in mind your own child's unique needs and his level of functioning as this will help in determining what type of guardianship is best.

Total guardianship. This form of guardianship is usually selected to protect the lifelong needs of a severely handicapped individual who is considered totally incapable of making his own decisions or managing his own affairs. Children who are profoundly retarded or otherwise severely impaired usually fall into the category of those who will require

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ABOUT THE AUTHORS

Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

total guardianship.

The first step in this legal process is for the courts to declare your special child **incompetent** and thus in need of a total guardian who will act on **all** decisions on his behalf. The disabled person who is declared incompetent loses the right to:

- vote
- marry without permission
- sign contracts
- choose a place to live
- choose a vocational program or place of employment
- sue or be sued
- consent for surgical procedures
- make a will
- buy or sell real estate

The total guardian makes **all** the above decisions on behalf of the handicapped person.

Partial/limited guardianship. Parents should consider this form of protection if their special son or daughter has the ability to make some independent decisions. In this type of guardianship, the courts do not make any determination of incompetency. Rather, the partial guardian only steps in to make decisions in those areas where it has been demonstrated that your son or daughter needs help. All other activities are left up to the disabled individual, permitting him as much freedom and self-esteem as possible. For example, your special child may be able to use public transportation, go to the place of employment he has chosen, live in an apartment or residence of his choice, but nevertheless require assistance from the guardian in handling money. Under partial guardianship, your special child would be protected from exploitation in a vulnerable area without limiting his bid for independence.

Collective guardianship/joint trust. This is the latest and most talked about form of guardianship. It is a system of both advocacy and guardianship that insures that a responsive organization rather than an individual will oversee your son or daughter's lifelong affairs.

The concept of an organized community trust has many advantages over an individual or court-appointed guardian:

- Most community trusts are staffed with skilled people conversant with the unique needs of the handicapped.
- Community trust staff and volunteers are under supervision and receive training in the specialized needs of the handicapped.
- Enrollment fees are usually affordable.
- Community trusts are more aware of the needs and rights of their handicapped members and thus can advocate as well as oversee.
- Trust funds are commingled (mixed with others) and are managed by people who are experts in the field of providing for the handicapped.

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Wills and trusts

The drafting of a will is always a sensitive issue. To examine one's own mortality, to consider family members fairly in making bequests is difficult at best, but becomes even more complicated when it entails making lifelong provisions for a special son or daughter. Most special parents, once they make a will, feel that everything has been taken care of. Unfortunately, this is not the case!

While each state has its own regulations that should be investigated carefully, attorneys as a general rule caution special parents about willing sums of money or real property directly to their special child or adult. Making direct bequests often jeopardizes your special child's eligibility for many benefits. Instead, they recommend willing the property or money to a **testamentary trust** and that the trustees be given the sole discretion of acting on behalf of your disabled survivor.

Why set up a trust?

Setting up a trust will legally protect your special child's inheritance from being appropriated by the government or other creditors and at the same time allow for a higher standard of living. For example, if your special child resides in a state-funded community residence and you leave him a sum of money directly, the state has the right to seize that sum of money to offset basic room and board charges. If, however, that same sum of money is left to the trust, the funds can be used at the discretion of the trustee to purchase birthday presents, clothing and gifts, supplement pocket money and otherwise provide items that will enrich your child's life. Make sure that your trustee knows how you want the trust money to be used and under what conditions.

Specific trust provisions

The trust should set down provisions for the trustee to maintain close contact with your special son or daughter. Monthly or bimonthly visitations insure that your special one's needs are being looked after. Be aware that each state has its own regulatory procedures for the setting up of trust agreements. It's best to consult an attorney or organization that has specific expertise in estate planning for the handicapped. This is especially important in cases where, although the will and the trust agreement are drawn up in one state, your handicapped son or daughter lives in a residence or institution in another state with different laws.

Terminating the trust

Rules and regulations vary from state to state and it's important to keep in mind that court laws can change. If at any time state laws or court rulings render your special son or daughter ineligible for certain benefits, make sure you have given the trustee the right to terminate the trust. Make provisions beforehand to distribute what funds are left, either to siblings, relatives or someone else you designate.

Life insurance, other savings

The inadvisability of willing funds directly to your special son or daughter includes other kinds of savings. Make sure your special child or adult is not the direct beneficiary of your life insurance policy, stocks, bonds or savings accounts. Caution well-meaning relatives **not** to leave sums of money or property directly to your disabled son or daughter. This may well render him ineligible to secure vital local or federal benefits. If, for any reason, your special child has already accrued assets in his own name, spend his money, not yours, for his needs now.

Selecting a trustee or guardian

Generally speaking, the trustee administers or looks after the real property or other assets of your estate, while the guardian is more personally involved with your special son or daughter's rights and needs. In some cases, the trustee and guardian are one and the same; in other agreements, separate individuals or organizations take over the responsibilities.

The proper selection of the trustee and/or guardian is crucial. By making a careful selection you insure that not only will your parental wishes be respected, but that your disabled son or daughter will benefit from someone's careful guidance and protection. By specifically naming a legal guardian or trustee for your special child, you eliminate the need for the court to appoint a guardian—a process which often entails considerable fees. There is no guarantee that a court-appointed guardian has any knowledge of the handicapped or that your explicit wishes will be carried out.

The guardian's role

Your special child's guardian not only should have financial integrity, he or she should also be sensitive to the unique needs of your special child. The guardian should have the ability to be a friend, an advocate and a protector. A close friend of the family, a relative, or the disabled child's brother or sister are often good choices. Make certain that any person you select as the guardian of your child realizes he is not expected to take your special son or daughter under his own roof. Guardianship does not mean providing day-to-day personal care. The fullest definition of guardianship is advocacy and the ability to see that the wishes of the parent are carried out.

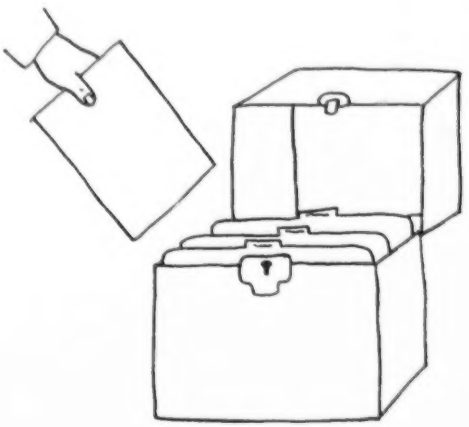
It is vital to name successors to your special child's designated guardian. In the event that your child's guardian or trustee falls ill or is unable to serve, someone else of equal merit should have agreed to step in.

Keeping records for the guardian

Make sure you have a packet or specific file on hand with all the records and information that your child's guardian will need to protect your child's rights and insure your wishes as the parent. This packet should contain:

- your special child's social security number. If he does not have a social security number, **get one now.** Your estate cannot disburse income on your special child's behalf unless he has a social security number.
- you and your spouse's social security numbers.
- your marriage certificate. If your demise occurs while your special child is still a minor, his benefits will be jeopardized unless your marriage certificate is available.
- your child's birth certificate.
- guardianship papers.
- names and addresses of professionals and schools that have records pertinent to your special son or daughter's disability.
- last federal income tax return and W-2 forms.
- veteran's discharge papers, if applicable. Many benefits are available to survivors of veterans.
- information about your special son or daughter's assets, if any, or information about any benefits you might be eligible for, such as social security or other entitlements.

Make sure the person you have asked to be guardian knows where you keep this vital statistics file. It's always a good idea to have copies of everything and to have a duplicate file readily available.



Other benefits

Your special son or daughter may be entitled to receive other benefits. If you have ever been employed by the railroads, federal or state government agencies or public school districts, you probably have amassed benefits that can be directed to your dependent disabled survivor. Check with your personnel officer if you are currently employed or go back to your previous employer and get the name and address of where to apply for such benefits. Make sure to include this information in your vital statistics packet.

Social Security and S.S.I.

Under Social Security coverage, upon your death or retirement, your adult handicapped son or daughter is entitled to receive monthly payments at the same rate given to minors.

Your special son or daughter might be eligible to receive supplemental security income (S.S.I.) which is not the same as Social Security. Money for S.S.I. payments comes from U.S. Treasury funds, whereas Social Security benefits are based on parent contributions during employment. Special payment rates for S.S.I. have been established for individuals who are blind, mentally disabled or mentally handicapped. Your disabled adult son or daughter may be eligible for both Social Security and S.S.I. payments in his or her own right. For more information contact your local Social Security office.

Do's and Don'ts

- **Don't wait.** It's not necessary or advisable to wait until your special child reaches the age of 18 in order to begin guardianship proceedings. Unforeseen events can and do occur so it's best to have selected the relative, friend or organization who will manage your special child's affairs.
- **Don't designate a guardian in your will.** You can only designate a guardian in your will while your special child is a minor. Once your special child reaches 18, legal guardianship must be validated in court.
- **Do take into consideration the needs** of your normal children and other family members in setting up the terms of a trust or will. Your normal children might need funds to go to college, buy a house or start a business and these needs are of equal merit.
- **Do go over the terms of the trust or the details of the will with the guardian.** Make sure the guardian is aware of your wishes in regard to the channeling of funds. The guardian should know what you expect of him or her, and also what are the specialized needs of your son or daughter.
- **Do make sure that the guardian realizes** he does not have to use his personal funds to manage your child's affairs.
- **Don't avoid the issue in the expectation** that your normal children will take over the active day-to-day care of their disabled sibling. This is unnecessary, unfair and is bound to be a source of resentment that in the long run does a disservice to everyone.
- **Do sit down with the entire family** and explain what safeguards you have undertaken

in providing for all the family members. Make sure your spouse or adult children know all the relevant information, i.e. names and addresses of law firms, guardians, authorized community trusts and where a packet containing vital statistics is kept.

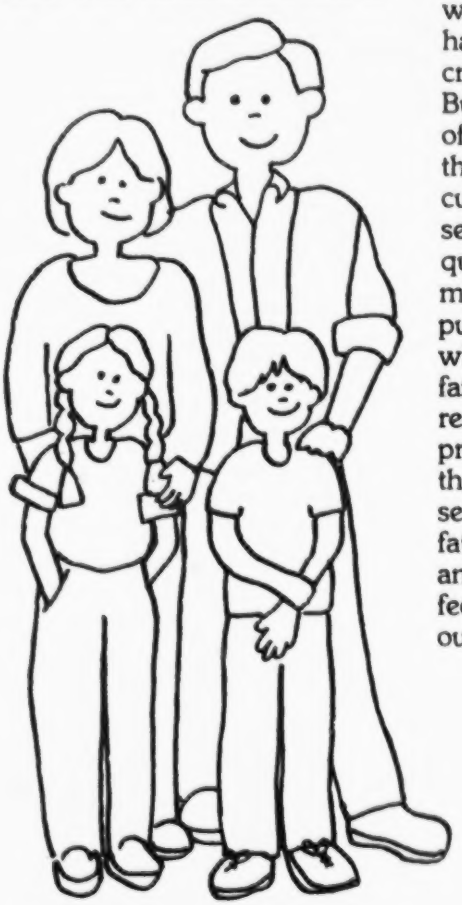
• **Do select an attorney** who is experienced in setting up trust agreements or wills for the handicapped. ARC, an organization for the handicapped with local chapters in many areas, can be of great assistance to you.

You can also contact the local chapter of the Bar Association in your area; this professional organization often has a lawyer referral service that can be of help.

Psychologist's Corner: BEING THE FATHER OF A SPECIAL CHILD

by George Popper, Ph. D.

Much has been said and written about being the parent of a handicapped child. Even though we live in a supposedly enlightened society in which men and women share equally in the raising of children, it is still usually the mother who assumes the role of primary caretaker and ends up with most of the work. Only recently has the role of the father been discussed in any detail. The purpose of this article is to talk about the importance of the father as a caretaker to a special child.



When new parents are greeted with the news that they have a handicapped child, it can be crushing and both parents suffer. But for the father, the impact is often different from the impact on the mother. The father's masculinity, his self-concept and his self-esteem are all called into question. To deal with this enormous emotional stress, some men put distance between themselves, what has happened and their family. Marital breakup often results. With children whose problems become more evident as they get older and are having serious difficulties at school, the father's reaction is sometimes anger, denial of responsibility, feelings of shame and guilt or outright avoidance. There is no

one answer to how one deals with such feelings, but being aware that they exist is a good first step. If these feelings are ever to be resolved, they must be dealt with, not avoided or ignored.

Most would agree that children need two full-time parents; this is particularly true for special children. Children look to their parents as role models. They need to know they are important and loved unconditionally by **both** their parents. We already know this, but it is good to be reminded from time to time. There is no magic to being a good father but these few points may prove to be helpful.

1. If you have a handicapped child, find out as much as you can about the handicapping condition. Seek out professionals, attend lectures, read books and articles and become as knowledgeable as you can. The more knowledge you acquire, the more confident you will feel and the more effective you will be in dealing with your child's problem.

2. Learn to think of yourself as part of the solution and not part of the problem. Many men develop a deep sense of guilt because they have an imperfect child. Perhaps they feel they did something wrong and they are to blame for the problem. While this is a very real and understandable reaction, it is important for fathers to begin to see themselves in terms of what they can do for their child rather than what their child has done to them.

3. Learn to enjoy your child. Handicapped or not, your child is still fun to play with. Your special son or daughter needs the feeling of closeness that comes from shared play, and so do you.

4. Fathers seem to have a special interest in having their children succeed. They want their children to do well in school, get a job and have a family. Coming to terms with what is possible and what is unlikely is sometimes very difficult but still very necessary. There is always a delicate balance between being overprotective and overdemanding. Educating yourself and keeping current go a long way toward developing a realistic approach.

5. For children to have two full-time parents, you and your spouse must work together. A cooperative effort, however you and your partner wish to do it, makes parenting easier and more effective.

6. Sometimes it's not easy being a parent. Like many fathers (and mothers), we are faced with self-doubt about whether or not we are doing the right thing or have done all that we could. Developing a network of professionals, getting to know other parents with similar problems and participating in a support group are all positive ways to deal with some of these fears.

7. A father once said that when he learned he had a handicapped child, he lamented, "Why did this happen to me?" It was when he was able to say, "Why did this happen to my child?" that he was finally able to become the father his child needed.